Author's response to reviews

Title: What aspects of periods are most bothersome for women reporting heavy menstrual bleeding? Community survey and qualitative study

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Author's response to reviews: see over
Thank you for your consideration of our paper. We found the referee’s reports very thoughtful and helpful. We have attempted to address them as far as we are able and detail how we have done this in the response below and with marked revisions in the manuscript. We have also made the formatting changes to the manuscript as requested.

Responses to Mark Shapley’s comments

Major compulsory revisions

Originality
Dr Shapley was concerned that the originality of the paper depends on the sample differing from samples of previous qualitative studies. We agree that this is an important point and welcome the opportunity to strengthen the case for the original contribution that this paper makes.

We believe that the originality resides not just in the sample but also in other features of this research.

1. An important original feature of this research is that it seeks to provide unique data that helps to unpick further the multi-faceted menstrual complaint, as experienced by women, from the traditional biomedical categorisation as either pain, PMS or heavy bleeding. That is, what is it that women find most bothersome about periods, in particular what is the most bothersome feature of periods for women reporting heavy bleeding on a community survey?

2. The 2nd feature of note is methodological. We would argue that a sample recruited through response to a community questionnaire is qualitatively different from a sample recruited through a consulting population. This is because the context of research can influence both the decision to participate, and the nature of the responses, most probably via the differing salience of symptoms/problems. The fact that our respondents have not been selected as consulters frees them from any perceived obligation to present a symptom profile in support of such action.

With regard to the sample, Dr Shapley asks whether or not we have excluded ‘consulters’. We make two comments on this important point.

1. Women included in this sample had reported heavy or very heavy menstrual loss, so it would be surprising if they had not sought medical advice at some point. If we excluded all women who had consulted at some point, we would no longer have a community sample of women reporting heavy menstrual bleeding but, rather, an unusual sample of ‘non-consulters despite heavy or very heavy periods’. Thus we defend the inclusion of some women who had sought medical help with their problems, and detail this in our next comment. We feel that both our survey and interview research show that even among women reporting heavy bleeding a range of symptoms associated are important, in having an impact on everyday life. Although this is similar to those of other studies, it allows the generalisation of the findings beyond consulting samples. However, this would not be possible unless the paper reaches a peer reviewed journal.
2. As we have said, because they had reported heavy or very heavy bleeding, many women were likely to have reported having consulted at some point. For example, in the qualitative sample some women (12/32) reported having consulted in the last 6 months, and some (a further 12/32) at some point in the past. If the referees and editors would like us to clarify this point in the text we can do so by adding the highlighted sentence to the methods section:

... The qualitative sample was chosen such that all had reported their periods as heavy on a fixed choice questionnaire item and approximately half (14 of 32) had reported marked or severe period pain. Initial interviews were carried out amongst women who had or had not reported their periods as a problem but it transpired that more data was generated from those who had reported a problem. Later interviewees therefore focussed on this group such that 26 out of 32 of the final sample had reported periods as a problem. Overall, according to their questionnaire responses, 12 interviewees had consulted their GP about periods within the previous 6 months. Of those who had not reported consulting on questionnaire, a further 12 said at interview that they had discussed periods with their GP at some point in the past.

We would welcome guidance on whether to make this change given that it entails the addition of a further 48 words to the manuscript.

Conclusions
We feel that our research highlights the importance of broadening the professional understanding of menstrual symptoms to reflect women’s wider concerns and that this is an important point in extending the understanding already gained from other qualitative studies. This is highly relevant to any consultations that occur. However, we agree that we may have gone beyond our findings and have therefore modified the final paragraph of the discussion, as below. We share Dr Shapley’s concern about the provision of more information regarding self care for menstrual symptoms and are addressing this in another paper.

We found that the impact of a range of menstrual symptoms were important in understanding the concerns of women with heavy menstrual bleeding. Findings from studies of patient-centred consulting in other conditions suggest that a better understanding of the patient’s illness experience contributes to improved patient satisfaction and outcomes (11). This would suggest that women would be helped by clinicians listening to women’s accounts of their menstrual problems in their broadest sense, clarifying presenting symptoms and their impact on everyday life, and offering help and advice for these. Further research would help to explore different ways of delivering information to women to support self care and help them to manage menstrual problems themselves, as far as possible.

Minor essential revisions
We have completed these revisions.

**Discretionary revisions**

1. **Abstract**
   We have re-worded the first sentence of the results section to try to make it clearer that this sentence refers to the quantitative data while the remainder refers to the qualitative data.

2. **Background**
   Thank you for highlighting the need to reference the most recent National Morbidity Survey. We have changed our text accordingly.

3. **Methods**
   We have added that we used computer-generated random samples.

We have given more detail on the process of validating the coding classification of free-text responses:

   In order to explore what constituted ‘problem’ periods among a large sample of women experiencing heavy menstrual bleeding, a free text question asked, ‘What bothers you most about your periods?’ This generated a wide variety of responses which were then coded. Coding schemes were developed by looking at 100 questionnaires and developing categories representing responses until these appeared to be saturated. Coding schemes were then checked with two other researchers for face validity. Categorisation involved difficult decisions; for instance, some had written ‘can’t be bothered with anything’, or ‘PMT’ which could be interpreted as either mood changes or tiredness...

4. **Results**
   Dr Shapley asks for more detail on differences between responders and non-responders. To do so we have added the following to the end of the second paragraph of the discussion:

   Furthermore, although a response rate of 61.5% is about that which might be expected for a community survey on a topic which is not necessarily relevant to recipients, this does raise questions about non-responders. We have shown elsewhere that non-responders were younger and likely to be living in an area of greater deprivation as calculated on the basis of postcode. They may have differed from responders in other ways also, with potential impact on our findings.

**Responses to Sioban Harlow’s comments**

**Major compulsory revisions**

1. **Concern over lack of consistency in the presentation of numbers in the sample.**
   Professor Harlow writes that the numbers presented are not consistent between abstract, methods and results and we attempt to clarify this in the paper as follows:
In the methods section we write:

A computer-generated random sample of 250 women aged 25 to 44 was selected from each of 19 general practice lists in Lothian, UK. If practices had fewer than 250 women in the target population all women in the age range were included. After exclusions, this resulted in 4610 questionnaires being sent with one reminder. The data presented here are derived from questionnaire responses from the 906 women who reported their periods as ‘heavy’ or ‘very heavy’ on a fixed choice question. Full details of this survey have been reported elsewhere (1).

In the results section we provide the denominator when describing the response rate in order to try to make the link between sample and response clearer.

In total, 2833/4610 women returned a completed questionnaire (response rate 61.5%), of whom 2574 reported having periods in the previous six months. Of these, 906 (35.2%) reported their periods as heavy or very heavy.

2. Discussion of the implications of non-response for the sample
We agree that this is an important point and have addressed it by amending the second paragraph of the discussion detailed above.

3. Detail on the distribution of heavy vs. very heavy
Professor Harlow pointed out that the concerns of women with ‘heavy’ vs. ‘very heavy’ loss might differ and that this would be of clinical importance. This is indeed the case and the second paragraph of ‘results’ and corresponding table have been changed to:

Table 1 shows the distribution of responses to the question ‘What bothers you most about your periods?’ There was a response rate of 89.6% to this question with 94/906 women either leaving it blank or writing ‘nothing’. Amongst women who had reported heavy or very heavy menstrual bleeding, pain remained the first concern for the greatest number with heaviness written by substantially fewer. Mood changes / tiredness were important to almost as many as heaviness. Overall, 44% (399) wrote in one thing that bothered them; 36.3% (329) wrote two things and 9.3% (84) wrote three or more things. Looking at whether an item was written in at all, rather than written as the first item, pain was written by 39.1% (354) and it appeared that mood changes / tiredness bothered marginally more women than heaviness (31.2% (282) compared with 29.0% (263)). If the subset of women who reported very heavy periods at survey is examined, it can be seen that for them, while heaviness was the aspect of periods most often identified as ‘most bothersome’, fewer than half did so (43%).
Table 1
Free text responses to question “What bothers you most about your periods?”

<table>
<thead>
<tr>
<th>What bothers you most about your periods?* (First item written in)</th>
<th>Women reporting heavy or very heavy menstrual bleeding</th>
<th>Women reporting very heavy menstrual bleeding</th>
<th>Women reporting heavy menstrual bleeding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
<td>% of 135</td>
</tr>
<tr>
<td>Pain</td>
<td>248</td>
<td>27.4</td>
<td>21</td>
</tr>
<tr>
<td>Heaviness</td>
<td>178</td>
<td>19.6</td>
<td>44</td>
</tr>
<tr>
<td>Mood changes / tiredness</td>
<td>158</td>
<td>17.4</td>
<td>10</td>
</tr>
<tr>
<td>Irregularity or other issues of timing</td>
<td>98</td>
<td>10.8</td>
<td>13</td>
</tr>
<tr>
<td>General inconvenience</td>
<td>52</td>
<td>5.7</td>
<td>2</td>
</tr>
<tr>
<td>Breast pain/swelling</td>
<td>25</td>
<td>2.8</td>
<td>2</td>
</tr>
<tr>
<td>Accidents</td>
<td>12</td>
<td>1.3</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>41</td>
<td>4.5</td>
<td>2</td>
</tr>
<tr>
<td>Blank</td>
<td>94</td>
<td>10.4</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>906</strong></td>
<td></td>
<td><strong>135</strong></td>
</tr>
</tbody>
</table>

4) These findings are presented in our paper published in the Journal of Clinical Epidemiology, as referenced.

5) These findings are presented in our paper published in the Journal of Clinical Epidemiology, as referenced. The relevant paragraph in that paper is as follows:

Periods were reported as a marked or severe problem by 22% (95% CI 20% to 23%) of menstruating respondents, 37% of women reporting heavy periods, 83% of women reporting very heavy periods, 75% of women reporting severe pain, and 61% of women reporting periods lasting 8 days or more. Reporting a combination of symptoms increased the likelihood of reporting ‘problem’ periods. For example, amongst women reporting both severe pain and very heavy periods, 95% reported their periods as a marked or severe problem.

6) We would have liked to present data linking women’s concerns with help-seeking but felt that it was not the main focus of this paper and might better form a separate paper. To include it here would involve presentation of a great deal more data which would be difficult to fit into this paper within the journal constraints on paper length.

7. Is ‘volume of loss’ rejected clinically?
In making this point in our discussion we were summarising work published by one of the authors where it was found that neither predictability nor gushing are strongly indicative of volume (reference 13) and by other authors who have found consulters for menorrhagia themselves are critical of doctors’ focus on absolute volume (reference 5). In light of Professor Harlow’s comments, we have changed the wording as follows (from 1st paragraph of page 11):
Among women consulting for menstrual problems the clinical focus on absolute volume of loss has been rejected in favour of a consideration of the overall impact of heaviness on everyday life elsewhere (5, 13).

Professor Harlow also raises the concern that we do not really know what women mean by heavy/very heavy. We feel that this paper makes an important contribution to exploring what women mean by heavy periods. The qualitative part of the paper considers this issue and the difficulties women have judging heaviness of loss. We have clarified this issue within the quantitative data by adding the highlighted text to the methods section:

A computer-generated random sample of 250 women aged 25 to 44 was selected from each of 19 general practice lists in Lothian, UK (or all women in target age range if fewer than 250). After exclusions, 4610 questionnaires were sent with one reminder. The data presented here are derived from questionnaire responses from the 906 women who reported their periods as ‘heavy’ or ‘very heavy’ on a fixed choice question which asked with respect to their periods over the previous six months; ‘How heavy are your periods? (light loss; moderate loss; heavy loss; very heavy loss)’.

Minor essential revisions

Definition of ‘PMT’
We do not use the term ‘PMT’ except where we are referring to survey respondents’ written responses to a free text question. This is what women wrote and for us to define what we understand by this term would not provide further insight, given that we were not able to interview all survey respondents.

Discretionary revisions
We have relabelled the ‘irregularity’ category, changing it to ‘irregularity or other issues of timing’ throughout.